A SELF-DIRECTED, ON-LINE TRAINING PROGRAM FOR CHINESE AND LATINO DEMENTIA FAMILY CAREGIVERS

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Why this is important to me
Dementia-related challenges facing Canada

- Number of Canadians living with dementia is rising sharply
- From 747,000 in 2011 to 1.4 billion in 2031
- Shift from LTC to home/community based care
- Increased pressures on family caregivers
- From $444 million unpaid hours a year of caregiving in 2011 to $1.2 billion in 2040

(Alzheimer’s Association, Canada)
What can be done?

Prevention – to increase physical activity

Prevention – program to delay dementia onset

Support – caregiver skill building and support program

Support – system navigator program

“A caregiver skill building and support program would yield a 30-year value of $63 billion dollars”

(Rising Tide: The Impact of Dementia on Canadian Society, Alzheimer’s Society, Canada, 2010)
Challenges for family caregivers

- **What caregivers do:**
  - Manage ADLs - feeding, dressing, grooming, walking, bathing, and assistance toileting
  - Manage IADLs - shopping, food preparation, housekeeping, laundry, transportation, and giving medication
  - Manage behavioral disturbances
  - Provide companionship or supervision

- **Challenges:** social isolation, work-life balance, lack of skills

- **Consequences:** increased depression, impacts immune system, increasing risk for chronic disease, increased mortality

- **What caregivers need:** knowledge, support, and skills to provide care
Types of Caregiver Training Interventions

- Caregiver Participation
- Education
- Social Support
- Skills training
Latino website for dementia caregivers: advancing knowledge

Secciones Nuevas:

La importancia de un grupo de apoyo

En el 2010 fueron diagnosticadas alrededor de 35 millones de personas en el mundo, con la enfermedad de Alzheimer. Se estima que en el 2030, la enfermedad de Alzheimer afectará a más de 65 millones de personas, y en el 2050, este número crecerá hacia 100 millones de personas. Esto equivale a 1 de cada 10 personas sobre la edad de 65.

Mientras el número de personas afectadas por esta enfermedad crece, también lo hace el número de cuidadores. De hecho, se estima que por cada persona con esta enfermedad, se necesitan 3 cuidadores.

El trabajo de los cuidadores, se hace más difícil al no tener un acceso fácil a la información. Esto hace necesario la existencia de una comunidad en línea para cuidadores.

El Internet ha hecho posible esta comunidad. CuidateCuidador se esfuerza por ofrecer información básica, apoyo y el consejo de expertos en el cuidado de Alzheimer. La página web provee:

- Información sobre la enfermedad
- Destrezas para el cuidado
Cuidatecuidador facebook community: providing support
Chinese website for dementia caregivers: advancing knowledge
Loveandhelp Sina Weibo Community: providing support
Needs Assessment

- In analyzing the Weibo dialogues, and other needs assessments through focus groups, we found:
  - Widespread needs among caregivers to improve care skills
  - Great individual variations in needs for improvement (e.g., those receiving diagnosis vs. those in late stage)
  - A need to make training courses more engaging so that the caregiver will be motivated to learn through the training materials
Towards an effective training program: self-directed learning

- Move from one size fits all to **customization** of educational content that meets unique needs of caregivers, given progressive nature of dementia, varying experiences and capabilities of caregivers, and is sensitive to cultural beliefs and values
- Move from passive learning to having caregivers **actively participate in learning process**
- Move from generic end of training evaluation to ongoing evaluation that **allows learners to monitor their own learning process** based on **personalized feedback**
Self-directed online training

Videos recommended based on needs assessment
Strategies to engage users

- Assess user needs to customize training course
- Use short video clips to allow flexibility of learning at the time and pace of their own choice;
- Use scenarios, challenge tasks, imaginary role plays, conceptual theme analysis, and interactive quiz
- Function that allows learners to track progress in learning activities
- Use recommendation algorithm to help learner transition from one topic to the next
- Use email reminders to help re-engage the learner when he/she becomes disengaged
- Cultural adaptation of the training content by addressing culturally specific issues of the ethnic Chinese and Latino family caregivers.
Challenges

- How to reach caregivers in need?
- How to keep them engaged in learning?
- How to help them transfer their learning to practice of care?
- How to incorporate user experience into the continuous improvement of the training course?
- How to sustain the training program?
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NIH R44AG026815; R44AG020869